

# HELPING IMPROVE THE LIVES OF EVERYONE AFFECTED BY POLYCYSTIC KIDNEY DISEASE

Our year in review

Trustees' Annual Report – 1 April 2017 to 31 March 2018



## **ANNUAL REPORT AND ACCOUNTS 2017-2018**

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## REFERENCE AND ADMINISTRATIVE INFORMATION

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[pkdcharity.org.uk](http://pkdcharity.org.uk)

### Polycystic Kidney Disease Charity

Registered charity in England and Wales

Number 1160970

Registered charity in Scotland

Number SC047730

A company limited by guarantee

Registered company in England and Wales

Number 9486245

### Directors\* and Trustees who served during the year

Mr Alan Greenberg (Chair, appointed Sep 2017)

Ms Maureen Carson

Mrs Alison Carter

Mrs Edwina Graham (resigned Feb 2018)

Mr Raj Johal

Mr Sarbjit Johal

Mr Barry Harpham (resigned Aug 2017)

Ms Rebecca Murphy-Peers

Mr Adrian Tinsley (appointed Mar 2018)

Mr Nicholas Tracey (Treasurer)

Mrs Christine Wallach (resigned Nov 2017)

### Research Advisory Board

Professor Pat Wilson (Chair)

Dr Anand Saggar (Vice-Chair)

Ms Sanela Becar (Lay Member)

Dr Jill Norman

Dr Richard Sandford

Dr John Sayer

Dr Paul Winyard

### Management & administration

Ms Tess Harris, Chief Executive (contractor)

Ms Esther Wright, Fundraising (contractor)

Ms Esther O'Brien, Support Services Coordinator (contractor)

### Patrons

Rt Hon Sir Vince Cable, MP

Professor Albert Ong

Dr Anand Saggar

Dr Richard Sandford

Prof Pat Wilson

### Professional advisors

#### Bankers

CAF Bank Ltd

25 Kings Hill Avenue

West Malling

ME 19 4JQ

#### Accountants

PEM

Salisbury House

Station Road

Cambridge, CB1 2LA

#### Independent accounts examiner

Charles Pickin

Fellow of Institute of Chartered Accountants in England and Wales

Harrison Jasper Ltd

Florance Lane, Groombridge, TN3 9SH

\*The directors of the charitable company (the charity) are its trustees for the purpose of charity law.

## TRUSTEES ANNUAL REPORT & DIRECTORS' REPORT

The Trustees, who are also directors of the Charity for the purpose of the Companies Act, present their annual report and financial statements of the Charity for the year ended 31 March 2018. The accounts comply with the Charities Act 2011, Companies Act 2006 and the trust deed, and follow the recommendations in Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

The Trustees confirm that they have complied with the duty in section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission in determining the activities undertaken by the Charity.

### **Chair's Report**

The PKD Charity is the only UK charity solely dedicated to the concerns of people affected by **polycystic kidney disease** or **PKD** – incurable, genetic long-term conditions which are a common cause of kidney failure and affect other organs in the body. There are two main forms of PKD: Autosomal Dominant PKD (ADPKD) and Autosomal Recessive PKD (ARPKD). You can read more about ADPKD and ARPKD below.

I am pleased to report that during the year, thanks to the generosity of our supporters and volunteers, we were able to continue our charitable work.

Key highlights included approving the award of a 3 year PhD studentship to study 'Molecular mechanisms of the Fibrocystin-*ATMIN* interactions in ARPKD'. ARPKD is the rare form of PKD and research into this sometimes devastating condition is sparse. *ATMIN* is a gene which interacts with the main gene that causes ARPKD and it is believed that *ATMIN* might be a useful target for novel therapies to treat ARPKD. Additionally, the charity, together with patients, participated in an international workshop on pain in ADPKD – a major complication of the condition which is hard to treat and can be highly disabling.

Over the next few pages you can read more about the charity's progress during 2017-18. We are unable to do our work without the generosity of those who donate money or give time: including patients and families affected by PKD, their colleagues and friends; the bereaved and those who give in memory of those who die from PKD; the healthcare professionals and researchers; our partners and foundations; our trustees and contractors.



Alan Greenberg, Chair, Board of Trustees

17 December 2018



## OUR OBJECTIVES AND AIMS

The Polycystic Kidney Disease Charity is the only UK charity solely dedicated to improving the lives of children, adults, families and carers affected by polycystic kidney disease (PKD).

### *Our charitable objects*

To promote health and to relieve those persons suffering from or affected by PKD with a view to improving their conditions of life, in particular but not exclusively by:

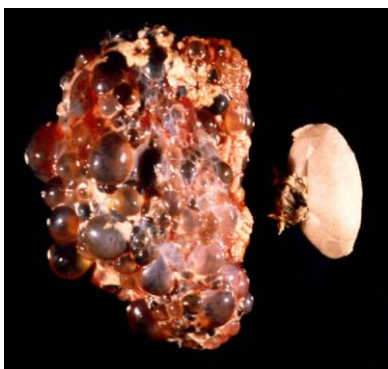
- Funding research into determining the causes of PKD and into discovering treatments and a cure, with any useful results of such research being available to the public;
- Promoting awareness of PKD through the production and publication of authoritative information for the general public and health professionals about the medical, healthcare and related aspects of PKD; and
- Organising patient, family and carer information, education and support events across the UK and offering personal support to patients and their families.

### *The challenge*

Up to 70,000 children and adults in the UK are thought to have polycystic kidney disease – a range of incurable, systemic genetic conditions that cause kidney failure and damage other organs. There are two forms of PKD: **autosomal dominant polycystic kidney disease (ADPKD)**, the most common inherited kidney disease and fourth cause of kidney failure worldwide; and the rare **autosomal recessive polycystic kidney disease (ARPKD)**.

Of the 800,000 babies born a year in the UK, we estimate that 800 – over 2 a day - could have ADPKD (based on 1 in 1,000 prevalence) and 20-40 could have ARPKD (1 in 20-40,000 prevalence).

**ADPKD** causes multiple fluid-filled cysts to develop, grow and multiply from birth in both kidneys resulting in kidney growth and progressive renal failure. In many patients, cysts also form in the liver, pancreas and other organs. Both kidneys can grow immensely, up to 100 times normal size (see image of ADPKD kidney compared with normal kidney). The brain and heart can also be damaged. Individuals with ADPKD will often have directly affected family members, parents and siblings, sometimes over several generations.



The majority of patients with ADPKD will have complete kidney failure by age 60, necessitating renal replacement therapy (RRT) to stay alive – either dialysis or (if feasible) a kidney transplant. Nearly 300 kidney transplants are performed annually. Some will require nephrectomies (kidney removal) due to organ size and cyst infections. Fifteen to twenty adults annually will also need a liver transplant owing to massively cystic livers. Some families are prone to brain aneurysms which can fatally rupture if not discovered and treated. Acute and chronic pain is common throughout life. As ADPKD progresses, individuals experience complications such as high blood pressure, infections, bleeding, anaemia, bone disorders, gout and kidney stones.

[Read more about ADPKD on the PKD Charity website.](#)



**ARPKD** is often diagnosed during pregnancy. Unfortunately, 1 in 3 babies will die before birth owing to the rapid growth of cystic kidneys preventing lung development. The babies who survive sometimes experience early kidney and liver failure. They may need life-saving dialysis before transplant and about a third have impaired growth during childhood. Some children may need kidney or liver transplants in later life. Despite this, many children do survive to adulthood with mild forms of ARPKD, although their kidneys and livers

can be impaired.

ARPKD patients frequently have very high blood pressure and are prone to liver-related problems such as bile duct infections and enlarged spleens. [Read more about ARPKD on the PKD Charity website.](#)

### ***Our Aims***

We want everyone affected by PKD to have the best quality of life, despite the complications and sometimes life-threatening nature of PKD. Being diagnosed with PKD is often a shock, even if there are known family members with the condition. People report feeling isolated and overwhelmed by psychosocial concerns for their own future, their children and family members. ADPKD patients often feel ‘genetic guilt’ because there is a 1 in 2 risk of passing on ADPKD. Families affected by ARPKD have to cope with often devastating consequences of the disease including possible early bereavement or the long-term implications of caring for a child with potentially life-threatening kidney and/or liver failure.

*The PKD Charity helps patients and families cope by providing up to date, accredited information, educational events and relevant support - personal or group, online and in person. Our aim is to improve knowledge and understanding of PKD, reduce anxiety and help everyone feel more confident about managing their or their loved ones’ condition.*

There have been major advances in understanding the genetic and biological nature of PKD in the past 40 years. The clinical characteristics are well known, but there is a wide variability of disease expression owing to genetic heterogeneity. For example, it is not unusual to see a significant difference between ages of kidney failure in ADPKD family members with the same PKD mutation. Therapies to modify and slow down progression in ADPKD are under study. However, there is only one drug (tolvaptan) which, in trials, slowed kidney cyst growth and is now licensed in the UK for a selected group of ADPKD patients. There are no disease-modifying therapies for ARPKD and very few studies worldwide owing to the small number of patients affected and the genetic variability. Dialysis or kidney/liver transplant are at present the only life-maintaining treatment when organs fail. Our aim to stimulate and fund more ADPKD and ARPKD research in the UK.

*The PKD Charity provides small grants up to £10,000 to UK researchers to ‘pump-prime’ projects that have potential for future funding (either from the PKD Charity or other funders). Applications are peer-reviewed by the charity’s Research Advisory Board. The charity also funds a PKD Biobank at the Royal Free Centre for Nephrology which can be accessed by*

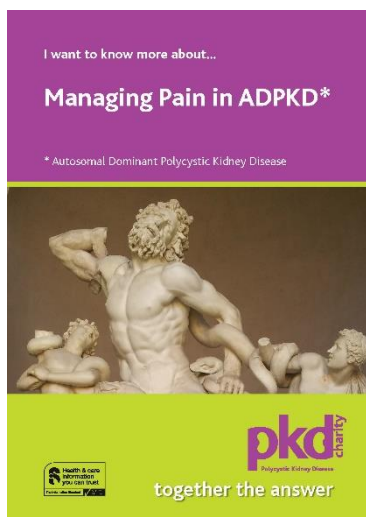
*researchers needing cells and tissue for ADPKD and ARPKD studies. The Biobank is curated by Professor Pat Wilson, the Research Advisory Board chair.*

Despite being a very common kidney disease, few people seem to have heard of ADPKD and awareness amongst GPs is known to be low. ARPKD is rarely seen and diagnosis can be a challenge, especially in pregnancy. We aim to raise awareness of the impact and burden of both conditions through authoritative information and targeted communications.

*The PKD Charity represents the views and voices of patients, families and carers to UK healthcare professionals, NHS England and policy makers. We seek to educate pharmaceutical firms with an interest in PKD to ensure that patients' needs and the PKD burden are well understood. Where appropriate, we work in partnership with other charities and umbrella groups. We also endeavour where possible to inform the general public about PKD.*

## PERFORMANCE AND ACHIEVEMENTS DURING 2017-18

### Activities in relation to information and support

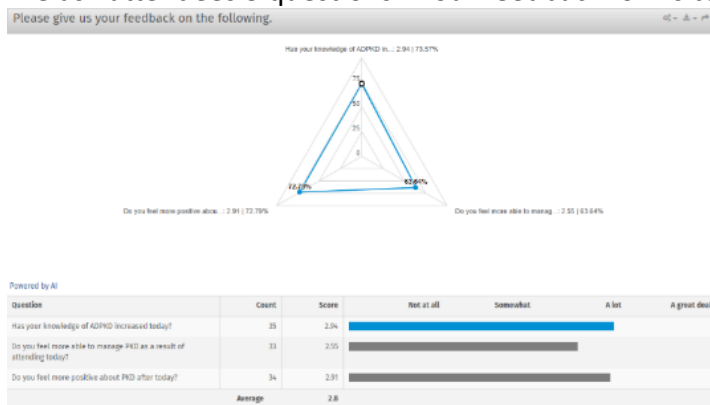


During the year, we continued to update and create **health information leaflets**, following an editorial process accredited under the NHS Information Standard. We have active lay and expert readers' panels who provide constructive feedback during the process.

These leaflets are freely available online and distributed at educational and awareness events. Healthcare professionals can download and order them online to give to their PKD patients during clinic appointments.

We held **ADPKD Information and Support Days** in London (Hammersmith and St George's hospitals) Birmingham Heartlands and Edinburgh, attended by nearly 300 patients and family members. Sessions include talks by kidney doctors, nurses and patients. Each event includes workshops to allow small groups to discuss in detail matters such as coping with ADPKD, pain, diet and lifestyle.

We ask attendees 3 questions in our feedback forms to assess the impact of these events:



- Has your knowledge of ADPKD increased today?
- Do you feel more able to manage PKD as a result of attending today?
- Do you feel more positive about PKD after today?

The majority felt more informed, confident and positive. We used all the feedback to improve subsequent events.

***"The information day on Saturday was so helpful. I cannot thank you enough for the extra knowledge and confidence it gave me to really make the most of my consultation with my new consultant today and also to know that there are people out there with a true understanding of how we can sometimes feel."***

We held an **ARPKD Event** at the Birmingham Children's Hospital (BCH) 'All Stars' family party. Ten families attended. Whilst the adults attended educational sessions with talks from experts and scientists, the children took part in supervised entertainment. Kidney Research UK kindly provided a grant towards the event to enable parents to travel to Birmingham; BCH provided catering and entertainment.



During the year, we provided personalised support by phone, email and our online support groups. 'Support' ranges from giving non-medical information or signposting to relevant materials (on our PKD Charity site or approved 3<sup>rd</sup> party sites) to 'listening'. On average, one person a day rings the charity helpline number - Monday is often a busy day; typically, the caller has spent the weekend searching the internet and is confused and concerned.

***"Thank you! Your advice was really helpful"***

On our website, we have installed a chat function, which acts as a 'triage' service. The operator is able to deal with simple requests – such as providing information about fundraising or signposting to information pages – allowing our chief executive to answer the more complicated or sensitive questions.

Our busiest support is delivered online, via the closed Facebook groups we have set up for patients, cares and parents of children/young people. We have restricted membership to people living in the UK to avoid confusion about healthcare systems that arise in international groups. Group members generally provide mutual and sympathetic support to one another. However, we monitor and moderate all posts, correcting factual misunderstandings/errors, signposting to reliable information/resources and offering personalised help to anyone who is particularly distressed. On average, about 10 people a day posted on the Facebook group, with up to 200 comments a day on these posts. The growth of Facebook has resulted in a significant decrease in posts on our old Yahoo forum (established more than 10 years ago).

***"This group/charity has been a lifeline for me."***

We also moderate HealthUnlocked ADPKD and ARPKD communities, which are hyperlinked from NHS Choices website. These are less active than Facebook and membership overlaps.





During the year, we completed the pilot of the Telephone Befriending Programme in London, the NW of England and Scotland, funded by the National Lottery Awards for All. We have trained nine befrienders in England and three in Scotland.

We streamlined the training process following feedback and began to use the online training provided by the Befriending Network. We established a Peer Support Steering Committee composed of trained befrienders, facilitated by the charity's Support Services Coordinator, who will help us further develop all our support services in future. One change recommended by the Committee was to change the word 'befriending' to 'peer support'; we have renamed the service accordingly. Those being supported appreciate the opportunity to speak one-to-one to someone who has similar lived experiences:

***"It was suggested I use the befriending service so I had someone that I could talk to who understood, because I am the only one in the family who has PKD. The service has been amazing. Having someone who understands the illness and has been through it as well is indescribable and after I spoke to the befriender I felt a sense of relief, I am happy."***

During the year, a number of local 'Meetups' took place in Birmingham, Bristol, Exeter, Falkirk, Southampton and Southend, with between 6 and 12 people at each. The meetups are hosted by trained volunteers. Post-meetup evaluation shows that people feel better informed and 'listened to'.

## **Activities in relation to research**

### **Grants awarded**

In September 2017, the trustees agreed to award £48,000 over 3 years, co-funded by the Arran Brown Rainbow Foundation, towards a PhD Studentship at the University of Wolverhampton. The student will study 'Molecular mechanisms of the Fibrocystin-ATMIN interactions in ARPKD' and be supervised by Dr Paraskevi Goggolidou. The research is expected to start in September 2018.

In January 2018, the trustees agreed to award £10,000 to fund a research nurse to help with the enrichment of the ARPKD paediatric cohort within RaDaR (National Registry of Rare Kidney Diseases).

### **PKD patient involvement in research**

In May 2017, the charity participated in a two-day pain meeting in Cambridge organised by Dr Thomas Hiemstra from Addenbrooke's Hospital. Eight ADPKD patients with experience of pain were recruited through the charity. Meeting attendees included international leaders in ADPKD and or pain research from the Mayo clinic USA and Groningen NL, and Cambridge-based experts in pain and clinical trial design. This group agreed that addressing the problem of pain in ADPKD was a priority. Dr Hiemstra proposed an initial observational pain study – called HOPE - to fully characterise ADPKD pain, utilising a bespoke pain assessment tool suitable for use in future clinical trials. Efforts are continuing to obtain funding for the study.

A kick-off meeting was held with a James Lind Alliance facilitator to discuss the ADPKD Priority Setting Partnership (PSP). Owing to the anticipated launch of the international SONG-PKD initiative to identify core outcomes for future studies and trials, it was agreed to defer the start of the PSP. SONG-PKD will conclude in January 2019 after which the UK PSP is expected to start.

In June 2017, the charity attended the UK Kidney Week Conference in Liverpool and presented a poster (right) on untreated pain in ADPKD, using data from a survey of supporters.

The charity supported two research applications to the NIHR by Professor Alison Metcalfe (King's) and Professor Paul Winyard (Institute of Child Health), relating to the management of children and young people with ADPKD. A number of patient involvement activities took place including surveys and engagement with young people at Great Ormond Street Hospital.



Professor Pat Wilson reported on utilisation of the charity-funded PKD Biobank, held at UCL Centre for Nephrology Royal Free Hospital. Over 700 samples were provided for use in 18 PKD-related projects in the 12-month period of 1/12/2016 to 30/11/2017. Since 2013, the Biobank has provided 2,064 samples for 67 UK projects.

During the year, the charity represented patients and families on two clinical study groups:

- The **ADPKD Clinical Study Group (CSG)** sits within the UK Kidney Research Consortium (UKKRC). Its members are multi-disciplinary and include patients. Its role is to stimulate ADPKD research, provide peer review to researchers and endorse worthwhile studies. The CEO chairs the CSG. [More information here](#). The UKKRC met in June and December 2017. The CSG met several times during the year, mostly by phone.
- The **ARPKD Rare Disease Study Group**, which sits within RaDaR, chaired by Dr Larissa Kerecuk. [More information here](#)



The CEO sits on the RaDaR Operating Management Board, which reviews registry progress, ethics and other matters.

The CEO represented the charity on the Renal Association working group developing a new UK guideline for the monitoring and management of children at risk of, or diagnosed with ADPKD. Two parents of children with ADPKD were recruited to join the group.

### **Activities in relation to awareness**

Throughout the year, we attended and participated in conferences, workshops and events relevant to renal and genetic conditions:

- June 2017: UK Kidney Week, Liverpool.

- July 2017: NHSBT Kidney and Liver Patient Support Groups meetings.
- July 2017: Transplant Games in North Lanarkshire.
- September 2017: European Society of Paediatric Nephrology, Glasgow.
- October 2017: NKF Annual Conference.
- October 2017: Presentation to Vertex Pharmaceuticals.
- November 2017: Multi-disciplinary Workshop on ADPKD (organised by Otsuka Pharmaceuticals UK)
- January 2018: Kidney Health Partnership meeting.
- January 2018: Renal Transplant Services Meeting.
- February 2018: Rare Disease Day.
- March 2018: World Kidney Day.

During the year, we published and distributed two issues of the PKD Charity newsletter to approximately 3000 households, the 80 main renal hospitals and over 200 dialysis units in the UK.

The charity participates in the **European ADPKD Forum (EAF)**, a collaborative initiative launched in 2014, to raise awareness of ADPKD and its implications for patients, health services and economies in Europe — issues that are often under-recognised by many health stakeholders and policymakers. The CEO co-chairs the EAF with Dr Richard Sandford. During the year, the EAF worked on a Multidisciplinary Statement on ADPKD care, which was [published in NDT](#).

In May 2017, European Reference Networks (ERNs) were launched across the EU. ERNs are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources. ADPKD and ARPDK are included within the ERNs. The CEO represents patients in the ERNs for kidney (ERKNet) and Rare Liver. The impact of Brexit on continuing involvement is unknown.

### ***Governance activities***

During the year, three trustees resigned and two trustees were appointed following advertisement. We thank the trustees who resigned for their support and commitment over the years.

Mr Alan Greenberg was appointed chair of trustees in September 2017.

During the year, the trustees adopted the Charity Governance Code for Smaller Charities.

During the year, preparations were made for implementation of the GDPR in May 2018. This involved an audit of data and its purposes, using guidance published by the Information Commissioner's Office.

### ***Fundraising activities***

We thank all the amazing fundraisers who support the charity's work through a wide range of community activities and events: marathons, triathlons, runs, skydives, baking, school collections, etc. All fundraisers receive a pack with t-shirts and other items, plus sponsorship forms. Everyone is encouraged to sign Gift Aid declarations, an important income stream.

## ***Contribution made by volunteers***

We acknowledge and thank all our volunteers for their commitment and enthusiasm in supporting the charity's activities. In particular, the trustees thank: the healthcare professionals, scientists and others who gave their time to speak at the patient information events and wrote or reviewed health information materials; supporters who proofread communication materials; and especially the phone and online peer support mentors.

## ***Pro bono support***

We acknowledge and thank:

- Microsoft, who provide software free of charge or at minimal cost.
- QuestionPro, who provide a free-of-charge survey platform.
- Vidahost, a hosting company, which gave a charity discount on the usual cost of server space for the charity's CRM database (Harlequin).
- Google (AdWords advertising grant).
- Virgo, a communications agency, who provided pro bono digital support.
- Otsuka Pharmaceuticals UK, who provided funding to an agency to develop a digital campaign to raise awareness of PKD.

## ***Future plans***

- We will continue to hold Information and Support Days.
- We will proactively market our range of Support Services providing practical, emotional and social support: online, by phone, webinars, meetups.
- We will increase the number of research grants awarded, in particular looking at how we can support research into ARPKD and RaDaR.
- We will seek ways to measure our impact and communicate this more proactively with supporters and beneficiaries.
- We will continue to work in partnership where possible with other kidney and genetic charities.
- We will implement GDPR.
- We will develop and expand our fundraising activities outside our community to help ensure sustainability of our work.

## **STRUCTURE, GOVERNANCE AND MANAGEMENT**

### ***Constitution***

The Polycystic Kidney Disease Charity is a company limited by guarantee on 12 March 2015, Company Registration No 9486245 and is registered for charitable purposes with the Charity Commission, Charity Registration No. 1160970. The charity is governed by its Memorandum and Articles of Association. In the event of the Charitable Company being wound up, company members are each required to contribute an amount not exceeding £10.



## ***Trustees***

Trustees, who are also directors of the Charitable Company, are recruited and appointed by the other trustees. Most current trustees either have PKD or a family connection to PKD. They are unpaid volunteers and may claim reasonable out of pocket expenses. The charity's activities are planned and carried out by the trustees.

In 2017-18, there were 11 ordinary trustee meetings (two face to face) and no special meetings. The trustees make extensive use of teleconferencing and email communications. In September 2017, the trustees appointed Mr Alan Greenberg as chair of trustees.

All trustees are required to declare relevant interests and may be required to withdraw from trustee meetings.

All trustees are encouraged to develop their trusteeship skills and to attend external conferences and events relevant to PKD and charity governance.

## ***PKD Research Advisory Board***

During 2017-18, the PKD Charity Research Advisory Board met to review grant applications. Members also contributed to new or updated patient information materials (in line with our Information Standard accreditation).

## ***Management and Administration***

The Trustees delegate the management of charitable activities and administration to three part-time contractors: Ms Tess Harris, who provided chief executive, operational and administrative services; Ms Esther Wright, who provided community fundraising services and Information Day event management; and Ms Esther O'Brien, who coordinated the support services. The trustees monitored the activities and outputs of the contractors through reports provided at trustee meetings; the chair has regular phone and face-to-face meetings with Ms Harris. Since the year-end, the trustees hired a new contractor (in place of Ms Wright) to manage the charity's fundraising and an agency to provide trusts and foundations fundraising support.

The charity's bookkeeping and accounts are carried out by PEM.

The charity is a member of the **Fundraising Regulator**, providing reassurance to supporters, members of the public and other donors, and promoting best practice in fundraising.

The charity is certified by the **Information Standard** as a provider of 'high quality health and social care information' since 2013. More information here: <https://pkdcharity.org.uk/about-us/information-standard>

The charity is registered with the **Information Commissioner** and all supporters' and stakeholders' personal data are maintained securely according to the Principles of the Data Protection Act. Following the year-end, GDPR was enacted in May 2018.

## ***Membership of Related Organisations***

The charity is a founder member of the **Kidney Charities Together** group of kidney charities, who meet to collaborate on campaigns such as World Kidney Day, and consider ways to work together on initiatives to improve the lives of all kidney patients.

The charity is a member of several UK umbrella organisations representing the interests of people with long-term conditions (LTC) or genetic diseases, including **Genetic Alliance, the Health and Social Care Alliance Scotland, Rare Disease UK, the Kidney Health Partnership, the Specialised Healthcare Alliance and the James Lind Partnership**. The charity engages with these organisations to ensure that the charity's aims and activities are known, recognised and taken into account. The charity regularly inputs into national consultations facilitated by these umbrella bodies.

The charity is a founder member of the **Ciliopathy Alliance**, which brings together patients, families, doctors and scientists with the aim of improving the quality of life for children and adults affected by ciliopathies – primarily genetic diseases caused by defects in the function and structure of cilia (microscopic organelles found in every human cell and vital to development). PKD is an important ciliopathy with ADPKD having the largest patient cohort. More information here: [www.ciliopathyalliance.org](http://www.ciliopathyalliance.org)

The charity is a member of **Befriending Networks**, the UK's leading resource on befriending whose accreditation was obtained during 2015.

The charity is a member of the **ABPI (Association of British Pharmaceutical Industry) Patient Organisation Forum**. The forum meets regularly to discuss issues such as joint working between patient organisations and pharmaceutical companies. More information here: <http://www.abpi.org.uk/our-work/patient-organisation-forum/Pages/default.aspx>

The charity is a founder member of **PKD International (PKDI)**, a global alliance of patient groups supporting people affected by all forms of PKD. These groups have similar aims to the PKD Charity. The CEO is the current President of PKDI (a voluntary role). More information here: [www.pkdinternational.org](http://www.pkdinternational.org)

The charity is a member of **Eurordis**, the European umbrella organisation of patient groups representing adults and children with rare diseases. ARPKD is a rare disease, having a prevalence of 1 in 20,000. More information here: [www.eurordis.org](http://www.eurordis.org)

The charity is a founder member of **FEDERG**, the European Federation of Patient Groups representing rare and genetic renal diseases. More information here: [www.federg.org](http://www.federg.org)

## FINANCIAL REVIEW

### Performance

During the 12 months to 31 March 2018, the charity's income was **£181,591** (2016-17: £185,604).

Expenditure on raising funds as a percentage of total incoming resources was **21%** (2016-17: 30.0%), in line with the Trustees' commitment to fundraising effectiveness. Research expenditure **£36,166** (2016-17: £40,516). Research was funded out of Research-restricted reserves in addition to restricted funds from Arran Brown Rainbow Foundation. The charity increased its expenditure on charitable activities across Patient support, Awareness and Education to **£104,769** (2016-17: £98,099), including information days, telephone support, online/chat support and expenditure on the peer support service.

In total, the charity expended **£186,876** (2016-17: £207,342), resulting in a reduced deficit for the year of **£5,285** (2016-17: deficit £21,738). Total **fund balances carried forward at the year-end** was **£253,341** (2017: £258,626) and all funds maintained a surplus position at the year-end (Note 13).

### Public Benefit

All charitable activities are undertaken to further charitable purposes for public benefit. The trustees confirm they have referred to the guidance contained in the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives, and in carrying out and planning current and future activities respectively.

### Reserves

Trustees implemented a Reserves policy to hold reserves equivalent to a minimum 3 months' ongoing expenditure, after covering current liabilities. As at the year end, the charity had Unrestricted Funds of £89,506 (2017: £155,767), equivalent to 5 months' total expenditure net of current liabilities (2017: 9 months). The trustees considered that the charity had sufficient reserves at the year-end and are of the view that the charity continues to be a going concern.


### Risk Management

The trustees have overall responsibility for ensuring that the PKD Charity is managing risk in a professional, responsible and constructive manner. This has involved identifying risks the charity may face, assessing potential impacts and minimising them.

Material risks for PKD Charity include: key person dependency on its Chief Executive; risk of loss of supporters; managing regulatory changes such as GDPR; and maintaining a surplus. The trustees continue to review its succession plans and to survey the satisfaction of its beneficiaries and supporters, with a view to mitigating these risks.

The trustees regularly review the charity's risk management policies, which include data protection and safeguarding. The charity developed new GDPR policies. The charity is exposed to financial risks, such as loss of income, which it aims to mitigate by holding sufficient reserves while continuing to diversify fundraising, for example, by increasing grant funding.

### Approved by the Trustees and signed on their behalf by

  
Nicholas Tracey  
Trustee Treasurer

*on 17 December 2018*



## **Independent Examiner's Report to the Trustees of the Polycystic Kidney Disease Charity**

### **Independent examiner's report to the trustees of The PKD Charity**

I report on the accounts of the company for the year ended 31 March 2018, which are set out on pages 17-22.

### **Respective responsibilities of trustees and examiner**

The trustees (who are also the directors of the company for the purposes of company law) are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10 (1)(a) to (c) of The Charities Accounts (Scotland) Regulations 2006 (the 2006 Accounts Regulations) and that an independent examination is needed. The charity is required by company law to prepare accrued accounts and I am qualified to undertake the examination by being a qualified member of Institute of Chartered Accountants in England and Wales. Having satisfied myself that the charity is not subject to audit under company law and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the 2011 Act and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act)
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act
- to state whether particular matters have come to my attention

### **Basis of independent examiner's report**

My examination was carried out in accordance with the general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the next statement.

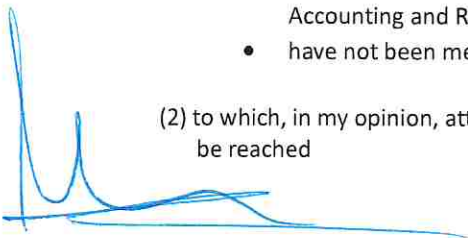
### **Independent examiner's statement**

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 386 of the Companies Act 2006 and section 44(1)(a) of the 2005 Act and
- to prepare accounts which accord with the accounting records, comply with the accounting requirements of the Companies Act 2006, section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations and
- which are consistent with the methods and principles of the Statement of Recommended Practice: Accounting and Reporting by Charities
- have not been met or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached



Charles Pickin  
Fellow of Institute of Chartered Accountants in England and Wales  
Harrison Jasper Ltd  
Florance Lane  
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## STATEMENT OF FINANCIAL ACTIVITIES - 1 APR 2017 TO 31 MARCH 2018

The notes on pages 19 - 22 form an integral part of these accounts.

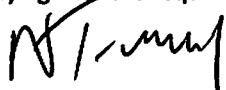
	Note	Unrestricted funds £	Restricted funds £	2018 Total Funds £	2017 Total Funds £
<b>Income and expenditure</b>					
Income from donations and legacies	2	145,640	31,976	177,616	180,449
Income from other trading activities	3	2,318	-	2,318	3,618
Investment income	4	1,657	-	1,657	1,537
<b>Total incoming resources</b>		<b>149,615</b>	<b>31,976</b>	<b>181,591</b>	<b>185,604</b>
<b>Expenditure on raising funds</b>					
Cost of fundraising	5	36,145	-	36,145	52,630
Non-charitable trading activities	5	1,892	-	1,892	3,130
		<b>38,037</b>	<b>-</b>	<b>38,037</b>	<b>55,760</b>
<b>Expenditure on charitable activities</b>					
Research and grants	6	166	36,000	36,166	40,516
Awareness and education		5,026	-	5,026	12,734
Patient support		93,595	6,150	99,743	85,365
		<b>98,785</b>	<b>42,150</b>	<b>140,935</b>	<b>138,615</b>
<b>Other Expenditure</b>					
Governance costs	7	7,902	-	7,902	12,967
<b>Total resources expended</b>		<b>144,724</b>	<b>42,150</b>	<b>186,876</b>	<b>207,342</b>
<b>Net incoming / (outgoing) resources for the year</b>		<b>4,891</b>	<b>(10,174)</b>	<b>(5,285)</b>	<b>(21,738)</b>
Fund balances brought forward at 1 April	13	155,767	102,859	258,626	280,364
Net incoming resources for the year	13	4,891	(10,174)	(5,285)	(21,738)
Transfers between funds	13	(65,000)	65,000	-	-
<b>Fund balances carried forward</b>	13	<b>95,658</b>	<b>157,685</b>	<b>253,341</b>	<b>258,626</b>

The statement of financial activities includes all gains and losses recognised in the year.  
All income and expenditure derives from continuing activities.

**BALANCE SHEET AT 31 MARCH 2018**

	Note	Unrestricted funds £	Restricted funds £	2018 Total funds £	2017 Total funds £
<b>Fixed assets</b>					
Tangible assets	9	2,116	-	2,116	4,416
<b>Current assets</b>					
Prepayments	10	11,163	24,000	35,163	15,267
Investments		-	-	-	75,000
Cash at bank and in hand		89,059	236,004	325,063	261,397
<b>Total current assets</b>		<b>100,222</b>	<b>260,004</b>	<b>360,226</b>	<b>351,664</b>
<b>Liabilities</b>					
Creditors: Amounts falling due within one year	11	12,832	44,169	57,001	77,454
<b>Net current assets</b>		<b>87,390</b>	<b>215,835</b>	<b>303,225</b>	<b>274,210</b>
<b>Total assets less current liabilities</b>		<b>89,506</b>	<b>215,835</b>	<b>305,341</b>	<b>278,626</b>
Creditors: Amounts falling due after more than one year	12	-	52,000	52,000	20,000
<b>Net assets</b>		<b>89,506</b>	<b>163,835</b>	<b>253,341</b>	<b>258,626</b>
<b>Represented by:</b>					
<b>Funds and reserves</b>					
Restricted funds	13	-	120,432	120,432	59,456
ADPKD Bio-resource Bank Grant Fund	13	-	13,403	13,403	13,403
PKD Registry	13	-	30,000	30,000	30,000
Unrestricted funds	13	89,506	-	89,506	155,767
<b>Total funds</b>	13	<b>89,506</b>	<b>163,835</b>	<b>253,341</b>	<b>258,626</b>

These accounts are prepared in accordance with the special provisions of Part 15 of the Companies Act relating to small companies. For the year ending 31 March 2018 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies. The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476. The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

  
Approved by the trustees on  
And signed on their behalf by  
**Nicholas Tracey, Trustee Treasurer**

*on 17 December 2018*

## **Notes to the Financial Statements for year ended 31 March 2018**

### **1a Accounting Policies**

The principal accounting policies adopted are as follows:

i) Basis of preparation

The financial statements have been prepared in accordance with the Statement of Recommended Practice, 'Accounting and reporting by Charities' (Charities SORP - FRS102), applicable accounting standards, the Charities Act 2011, Companies Act 2006 and the Financial Reporting Standards applicable in the UK (FRS 102). Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy or note.

ii) Going Concern

The trustees are of the view that the Charity holds sufficient funds to carry on for the next 12 to 18 months and that on this basis the assessment of the trustees is that the charity is a going concern.

iii) Incoming Resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received, any performance conditions attached to the item(s) of income have been met or are fully within the control of the charity and the monetary value of incoming resources can be measured reliably.

iv) Investment Income

Investment income is accounted for in the period in which the charity is entitled to receipt Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the Bank.

v) Resources Expended

Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Governance costs principally comprise Trustees' meeting costs, accountancy costs and professional fees.

vi) Grants

Provision is made for grants when the Trustees have made a binding commitment and this has been communicated to the applicant.

vii) Tangible fixed assets and depreciation

Depreciation is provided at rates calculated to write off the cost less the estimated residual value of each tangible fixed asset over its expected useful life as follows:

Computer equipment – 20% straight line

viii) Current asset investments

Current asset investments represent cash investments maturing within one year and are shown at carrying value.

ix) Debtors

Polycystic Kidney Disease Charity | Registered charity in England and Wales (1160970) | Registered charity in Scotland (SC047730) | A company limited by guarantee

Registered company in England and Wales (9486245) | Registered address: 91 Royal College St, London, NW1 0SE.

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

x) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

xi) Funds Structure

Funds are established to provide financial resources for aspects of the Charity's activities. Many Funds were set up when the Charity received grants and donations that were made for specified purposes. Where conditions were made, the Funds set up are Restricted Funds. The names of most of the Funds convey the purposes for which they were established.

**1b. Legal status of the Charity**

The Charity is a company limited by guarantee and has no share capital. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £10 per member of the charity.

	Unrestricted Funds	Restricted Funds	2018 Total Funds	2017 Total Funds
	£	£	£	£
<b>2. Income from donations and legacies</b>				
Donations and gifts	137,063	7,976	145,039	155,566
Trusts and foundations	-	-	-	-
Gift Aid	8,577	-	8,577	24,883
<b>Total:</b>	<b>145,640</b>	<b>7,976</b>	<b>153,616</b>	<b>180,449</b>
<b>3. Income from other trading activities</b>				
Other activities	-	-	-	-
Shop income	2,318	-	2,318	3,618
<b>Total:</b>	<b>2,318</b>	<b>-</b>	<b>2,318</b>	<b>3,618</b>
<b>4. Investment income</b>				
Interest income	1,657	-	1,657	1,537
<b>5. Expenditure on raising funds</b>				
Cost of fundraising	52,630	-	36,145	52,630
Goods sold	3,129	-	1,892	3,129
<b>Total:</b>	<b>52,630</b>	<b>-</b>	<b>38,037</b>	<b>52,630</b>



### 6. Analysis of Research and Grants:

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
PKD Bio-Bank	-	30,000
University of Cambridge (Smartphone app)	-	10,000
Research studentship grants	48,000	-
ADPKD Research	(22,000)	-
PKD Registry	-	-
ARPKD Research	10,000	-
Other costs	166	516
<b>Total:</b>	<b>36,166</b>	<b>40,516</b>

### 7. Governance costs:

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
Trustee meetings and governance	2,256	8,253
Accountancy and audit	4,760	3,000
Other professional fees	886	1,714
<b>Total:</b>	<b>7,902</b>	<b>12,967</b>

### 8. Taxation

The PKD Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or s256 of the Taxation of Chargeable Gains Act 1992 to the extent that these are applied to its charitable objects. No tax charges have arisen in the Charity.

### 9. Analysis of Movement of Fixed Assets

	<b>2018</b>
	<b>£</b>
	Office equipment
<b>Cost</b>	
At 1 April 2016	11,497
Additions / (Disposals)	-
<b>At 31 March 2017</b>	<b>11,497</b>
<b>Accumulated depreciation</b>	
At 1 April 2017	7,081
Charge for the year	2,300
<b>At 31 March 2017</b>	<b>9,381</b>
<b>Net Book Value</b>	
At 1 April 2017	4,416
<b>At 31 March 2018</b>	<b>2,116</b>

### 10. Debtors

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
Prepayments	11,163	10,709
Accrued income	24,000	4,558
<b>Total debtors</b>	<b>35,163</b>	<b>15,267</b>

### 11. Liabilities: amounts falling due within one year

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
Accruals and deferred income	12,832	20,979
Grant commitments	44,169	56,475
<b>Total current liabilities</b>	<b>57,001</b>	<b>77,454</b>

### 12. Liabilities: amounts falling due after more than one year

	<b>2018</b>	<b>2017</b>
	<b>£</b>	<b>£</b>
Grant commitments within five years	52,000	20,000

### 13. Funds and reserves

<b>Fund</b>	<b>Retained surplus at 1/4/17</b>	<b>Income</b>	<b>Expenditure</b>	<b>Transfer</b>	<b>Total funds at 31/3/18</b>
Activities	2,255	2,761	-	-	5,016
Harris	78	-	(78)	-	-
Research	20,346	-	(12,000)	65,000	73,346
PKD Bio-resource	13,402	-	-	-	13,402
PKD Registry	30,000	-	-	-	30,000
ARPKD	14,542	1,715	-	-	16,257
ADPKD	16,068	3,500	-	-	19,568
RFH Biomarker	94	-	-	-	94
A4A Lottery (England)	3,677	-	(3,677)	-	-
A4A Lottery (Scotland)	2,395	-	(2,395)	-	-
Arran Brown	-	24,000	(24,000)	-	-
Unrestricted	155,767	173,615	(144,724)	(65,000)	95,658
<b>Total funds</b>	<b>258,626</b>	<b>181,591</b>	<b>(186,876)</b>	<b>-</b>	<b>253,341</b>

### 14. Related party Transactions and Trustees Remuneration

Trustees received no emoluments (2017: £nil).